

## VA MULTIPLE SCLEROSIS CENTERS OF EXCELLENCE

## MS VETERAN

## SERVING THE HEALTH CARE NEEDS OF VETERANS WITH MS

## MY 70 YEARS LIVING WITH MS

I'm 88 years old and I've been living with MS for 70 years. I've fought for my country, traveled the world, raised a family, and have led a fulfilling life. I joined the Navy when I was 19 years old and WWII was starting to wind down. I was trained as a Recruit Training Command (RTC) radio technician and following my training, I was sent to the San Francisco Mare Island Naval Base where I was stationed on the light cruiser USS Vincennes.

My first encounter with MS occurred on the USS Vincennes. Our ships home port was Nouméa, New Caledonia in the South Pacific. The US was at war and the day soon came when the general quarters alarm sounded for everyone to get to their battle stations. As I heard the alarm and I saw my fellow crew members rush to their stations, I told my body to get out of bed, but I found that I couldn't. My left arm and leg were suddenly paralyzed. I couldn't get to my battle station.

When attendance was taken, the chief petty officer found me still in bed. I was sent to sick bay for 2 weeks and while there, I was examined by several doctors. Throughout the examinations, nobody was able to discover what caused the temporary paralysis; it was a mystery to them. I soon felt better and was back on my feet for duty. The War was over in August 1945 and in July 1946 I was discharged from the Navy.



Life wasn't quite the same when I returned home. I soon had another episode where my left arm and leg became paralyzed. My mother took me to the VA hospital in Brooklyn, NY, where I was examined by several doctors, but again, nobody could find the cause. It was difficult not knowing what was wrong,

but I was happy that I was quickly able to be up and about again. In 1947 I had another episode and was sent to the Brooklyn Jewish Hospital for a myelogram and spinal tap. Following the tests, at the age of 21, I was told that I likely had MS.

In 1947 doctors were still trying to better understand MS and there were no treatments available for the disease. My neurologist told me that my body might start to show some permanent disease progression in my forties, but for the next 20 years I would likely just have "attacks" that would last between 4-7 days. He told me that I would lead a normal life and it was good to have a better understanding on what was going on, as well as what my future might look like.

I've had MS relapses over the years, but I always felt better within a few days. In the 1970s I started noticing that my relapses were a little more frequent.

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## VISIT OUR WEBSITE

For additional information on MS, visit the VA MSCoE website at [www.va.gov/ms](http://www.va.gov/ms).

When walking, I found that my leg would drag sometimes and I was tripping and falling down. I traveled for work which made this difficult. I was in my mid-forties when my mobility started to decline and I have to admit it was tough dealing with the changes. For several years I used a cane to get around, then a walker, and for the last 4 years I've been in a wheelchair.

Having MS for 70 years has given me a birds-eye view on the progression of knowledge and treatments for the disease. Researchers discovered that MS was an autoimmune disease in the 1960s and the first treatment for MS became available in the early 1990s. Since there were no treatments for MS when I was diagnosed, I tried to live a healthy lifestyle and I think that helped. My diet was good and I watched my food intake to keep my weight in balance. I

stayed active and exercised whenever I could. I used to take B-12 injections and I still take a multi-vitamin and vitamin D supplement every day. I've never smoked cigarettes and drank maybe one alcoholic beverage a year. I haven't had a relapse in over 15 years and I've outlived four of my neurologists. Doctors talk more and more about diet, exercise, and vitamins now-a-days and I wonder if my lifestyle choices helped my MS.

Doctors told me early on that I would lead a normal life with MS and they were right. They say life is what you make of it and in my life, I've traveled the world, seen amazing things, and met wonderful people. I have a beautiful home and a remarkable family. I'm 88 years old, I've been living with MS for 70 years, and life is good!

*William Stavrakos - Bay Shore, NY*

## THE "OUCH" OF MS

Pain. Yes, a symptom experienced by over 60% of people living with MS. Pain is important because if left untreated pain affects relationships, mood, sleep, work, and the ability to have fun and generally enjoy life. Managing MS pain requires work. This article will describe MS pain and some strategies for treating MS pain.

### KINDS OF PAIN EXPERIENCED

A lesion or a disruption of central nervous system myelin is responsible for many MS symptoms and is one reason for the symptom of pain. A lesion in your brain or spinal cord can cause nerves to fire in a crazy fashion resulting in pain, called neurogenic pain. Pain may result from living with disability. Muscles, bones, or joints can be painful when stressed due to decreased mobility, long sitting, spasms, and improper use and disuse of these body parts. Then there is headache pain. People with MS seem to have more headache pain than people who do not have MS.

### RECOGNIZING AND UNDERSTANDING PAIN

It is important to be able to describe your pain in detail so your provider will know the best way of treating your pain. The most helpful way of relaying

what your pain is like is to keep a journal. Neurogenic pain is either steady and continuous or intermittent and spontaneous. Steady pain is described as burning, tight, tingling, nagging, aching, or throbbing. Most describe the steady pain as burning in the legs, feet, and hands, while some describe the pain as icy. The nagging sensations of crawling bugs, water running down an arm or leg, or tingling, pins and

### CAREGIVER AND FAMILY TELEPHONE CALL

Join the MSCoE free, monthly conference call to connect with caregivers and family members supporting people with MS. A variety of educational topics and resources are discussed.

**DATE:** 4<sup>TH</sup> MONDAY OF EVERY MONTH

**TIME:** 2 PM - 3 PM ET, 1 PM - 2 PM CT,  
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**TO PARTICIPATE:** CALL (800) 767-1750  
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The VA has a National VA Caregiver Support Hotline for caregivers and family members dealing with chronic illness. The Hotline toll-free number is (855) 260-3274 and it is open:

**MONDAY - FRIDAY:** 8 AM - 11 PM ET

**SATURDAY:** 10:30 AM - 6 PM ET

needles sensations can become so bothersome these are described and treated as pain. Steady pain is often worse at night, with temperature changes, and with exercise. Steady pain is more common than intermittent or spontaneous pain. Intermittent pain is described as stabbing, electric shock-like, or searing. This pain may occur in any part of the body, but often in the face (trigeminal neuralgia). When writing in your pain journal, describe the feeling, jot down when the pain starts and ends, and where on your body the pain is located. Record what makes the pain worse, what makes it better, and what you are using to decrease the pain. For instance, are you using a complimentary therapy like acupuncture or an over-the-counter treatment like ibuprofen or a muscle rub.

### TREATING PAIN

It is known that emotions such as anxiety, depression, anger, stress, and boredom can affect pain intensity. Lack of support, lack of sleep, and fatigue worsen the experience of pain. Recognizing the importance of general well-being means that in managing pain, your health care provider is going to understand you as a whole person. Your physical experience of pain, your emotional responses, and your support system are considered in pain management. Your pain is then tackled with an integration of medications, interventions to relieve anxiety and depression, and strategies to enhance social support and help you become more active.

Relaxation, meditation, imagery, hypnosis, distraction, strong beliefs or faith, and biofeedback are strategies that increase the tolerance to pain. Getting involved in work or social activities, joining a support group, or even having a good laugh are techniques that can minimize pain. Interesting to note, higher pain severity is reported by people with

MS who are unemployed or homebound. Physical agents work to enhance or limit pain transmitters and include the application of heat, cold, or pressure, physical therapy, exercise, massage, acupuncture, yoga, tai chi, and transcutaneous electrical nerve stimulation (use of electric current to stimulate nerves for therapeutic purposes).



Medication treatment of neurogenic pain is aimed at changing the crazy nerve firing. Drugs used for epilepsy help make nerve cell walls tight and stable. These also stop the wild nerve firing. Drugs for depression are used because the “feel good” neurotransmitters in your brain ease the perception of pain. The use of opioids remains controversial in MS pain management. Opioids or narcotics are considered when other agents become ineffective or not well tolerated. Narcotics may help you escape pain but can take away choice and true control over pain.

*In summary*, pain is a symptom that demands serious and ongoing attention, as it has such a pervasive impact on daily living. MS pain management is an achievable goal that integrates behavioral, emotional, and physical strategies as well as medications. The goal of pain management is to optimize mood, sleep, and quality of life. While MS pain is yours to own and ultimately you are the one to understand and make a difference in the pain experience, this is not something you need to do alone. Among many, your doctor, nurse, pain psychologist, physical therapist, spiritual advisor, friends, and significant other are there to help.

*Heidi Maloni, PhD, ANP - Washington DC VA*

## HOW TO BEAT THE HEAT

“Summertime ... and the livin’ is eeea-zzzyee ...” Most people living with MS would want to add another line about summer: “Oh no, it’s not! ... ‘cause I can’t stand the heee-eat ...” If you’re one of the many people who find that heat is a problem, here are some ways to be more comfortable this summer.

### HEAT AND MS

How does heat affect the human body? Simply put, nerves don’t work very well when it’s hot. Nerves with damaged or missing myelin sheaths -- as in MS -- are even more vulnerable to heat. People without MS can feel slow and foggy-brained when the temperature rises. So, it’s not surprising that people

with MS would be hit even harder. Symptoms of heat intolerance may include fatigue, muscle weakness, slowness, dizziness, increased heart rate, vision changes, and poor memory and attention.

### BE AWARE OF HEAT THREATS

Hot summer weather is the most obvious source of unpleasant heat. But watch out for some other, less common ways heat can sneak up on you:

- ▶ Hot showers or baths.
- ▶ Stuffy, warm rooms and elevators -- what might be comfortable for others may be uncomfortable for you.
- ▶ Meal preparation -- cooking, baking, or even hand-washing dishes in hot water.
- ▶ Sunshine -- even if you're not working hard, those "vitamin D rays" may be enough heat to cause problems.
- ▶ Illness -- bladder infections, a cold, or recovering from surgery may trigger a fever response.
- ▶ Physical movement -- sometimes just working around the home, walking, or rolling your wheelchair around is enough exercise to raise your body temperature.

### TIPS TO KEEP YOUR COOL

There are a variety of precautions and strategies you can implement to keep the heat at bay:

- ▶ Keep shower and bath water cooler than body temperature. Keep the bathroom fan on or open a window to help circulate air.
- ▶ When working in the kitchen, turn on a fan, take off that extra layer of clothing, and use cool or mildly warm water in the sink.
- ▶ Pace yourself so you won't get overheated. Plan to exercise or do chores in the morning when it's cooler, rather than later on when the temperature heats up.
- ▶ Dress in layers so you can quickly adjust clothing if you find yourself in a too-hot space. Wear lightweight, breathable clothing.
- ▶ Sip cool or iced fluids. Take it easy on anything with caffeine. Caffeine often increases urination, which may cause dehydration.

- ▶ Take a siesta in a cool place during the hottest part of the day.
- ▶ Turn on the air conditioning.
- ▶ Wear a wide-brimmed hat, and wear loose, light-colored clothing layers and sunscreen when outside. Stay in the shade if possible.
- ▶ Spray yourself with a plant mister/spray bottle -- it's a handy, low-tech way to cool yourself, and needs no batteries!
- ▶ Dip a cloth hat in cool water, wring out, and put on your head ... ah!
- ▶ Wear one or more items of cooling clothing.

### COOLING CLOTHING

A cooling vest, neck wrap, or other cooling garment might be just the right fit for your needs. Cooling garments help you "chill out," thanks to the cold packs that fit inside these specially constructed items. They may keep you cool for up to 3 hours, depending on the temperature and your activity level.

A vest is the most useful and commonly used design in cooling gear. Slip the frozen, cold packs inside your vest's pockets, and put it on about 30 minutes before you expect to need it, so you can get a head start on cooling. Wear a light layer underneath the vest or layer breathable fabrics over the vest if needed. Keep an extra set of cold packs in the freezer, ready to switch places with the first set.

### PERSONALIZE YOUR COOLING PLAN

There are a number of options to help you deal with the heat. For example, there are many different sizes and styles of cooling clothing available, from slim-profile to heavy-duty, bulkier models, depending on your needs. The VA generally covers adaptive devices such as cooling clothing and air conditioning units for people with MS. Other resources are the MS Association: [www.mymyaa.org/msaa-help/cooling/](http://www.mymyaa.org/msaa-help/cooling/) and the MS Foundation: [www.msfocus.org/Cooling-Program.aspx](http://www.msfocus.org/Cooling-Program.aspx).

Questions? Ready to start planning to beat the heat? Talk with your VA MS care team, and we'll work with you to help find the right combination of tactics and gear so you can beat the heat.

*Lynda Hillman, DNP - Seattle VA*

# ALEMTUZUMAB: A NEW TREATMENT FOR MS

Despite the approval of several new MS medications, many people with MS continue to have relapses and progression while on therapy. Alemtuzumab (Lemtrada™, AMB) is a new disease modifying therapy for MS recently approved by the US Food and Drug Administration (FDA) for the treatment of relapsing forms of MS. This may include relapsing-remitting MS and secondary progressive MS with relapses. Like other FDA approved medicines for MS, the goal of treatment is to prevent relapses and slow disability.

AMB works by reducing lymphocytes. Lymphocytes are cells of the immune system that cause inflammation. AMB is given as an intravenous infusion daily on 5 consecutive days. These infusions must be given at a certified infusion clinic familiar with the drug. Lymphocyte counts are lowest one month after treatment and slowly increase to normal levels over 12 months. The infusion can be repeated after one year with infusions on 3 consecutive days.

Two studies were completed to obtain FDA approval. One study looked at how the medicine works for people with MS who had not taken other medications. In the study, 581 people with MS were given either AMB infusions, or interferon beta-1a

(Rebif) three times per week. Interferon beta-1a is a commonly used, FDA approved medication for MS. The study followed people for 2 years. People treated with AMB had fewer relapses, reduced MRI activity, and less brain atrophy than people treated with interferon beta-1a. There was no difference in disability at 2 years. A second study tested AMB for people with MS who had recently had a relapse while taking another MS therapy. 840 people with MS were given either 12 mg or 24 mg of AMB infusions, or 44 µg of interferon beta-1a (Rebif) three times per week. People treated with 12 mg of AMB had fewer relapses, reduced MRI activity, and less brain atrophy than those treated with interferon beta-1a. The AMB group also had less disability at the end of the 2 year study.



People taking AMB had some significant side effects. The most common side effect was an infusion reaction. This may include fever, headache, nausea, or rash. These reactions can happen during or after an infusion. Your provider may decide to give you corticosteroids to lower this risk. An increased risk for infections was seen including respiratory and urinary tract infections. Other viral infections such as shingles or oral herpes infection are possible. Your MS provider may ask you to take another drug (acyclovir) to lower your risk of an oral herpes infection. There is also an increased risk of serious immune system diseases. These include thyroid disease, kidney disease, and blood disorders including low platelet counts. Platelets are important cells needed to form blood clots. An increased risk for thyroid cancer and melanoma has also been seen with AMB.

It is important to be aware of possible side effects after treatment has started. Before treatment your provider will check baseline blood and urine tests. This will assess blood cell counts and thyroid and kidney function. The blood cell count and urine tests should be repeated monthly, and the other tests should be repeated every 3 months, until 4 years after your last infusion. AMB is not recommended

## PATIENT EDUCATION TELEPHONE CALL

Join the MSCoE free, monthly conference call and learn firsthand about MS from MS experts and other health care professionals.

**DATE:** 2<sup>ND</sup> MONDAY OF EVERY MONTH

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in women who are pregnant or breast feeding. It is important to talk to your MS provider if you are pregnant or considering pregnancy. A risk management program for AMB has been developed for all health care facilities in the US. This program, called a risk evaluation and mitigation strategy (REMS), will monitor and help manage potential side effects.

*In summary*, AMB is a new disease modifying therapy that is FDA approved for relapsing forms of MS. While it has been shown to prevent relapses in many people with MS and possibly to prevent progression, it has serious side effects that need to be considered before starting the medicine. AMB has not been compared with treatments other than

interferon beta-1a (Rebif) in head to head trials, so the relative effectiveness of AMB to other MS therapies is unknown. Because of the many side-effects associated with AMB, it should be restricted to use in people with relapsing forms of MS who have failed other safer treatments. It also must be given by physicians familiar with its use, and close follow-up for side-effects is needed for 48 months after the last infusion of AMB. The VA pharmacy program is currently evaluating AMB and it may be available in late 2015. You should talk to your MS provider if you are interested in learning more about your MS treatment options.

*EJ Gettings, DO - Baltimore VA  
Mitchell Wallin, MD, MPH - Washington DC VA*

## NATIONAL MS SOCIETY VETERAN OUTREACH

The National MS Society is collaborating with the VA MS Centers of Excellence to support improved care and support services for Veterans with MS and their loved ones. Together, we are working to optimize health and quality of life for Veterans with MS.

The Society is a collective of passionate individuals who want to do something about MS now -- to move together toward a world free of multiple sclerosis. We help each person address the challenges of living with MS through our 50-state network of chapters. The Society helps people affected by MS by funding cutting-edge research, driving change through advocacy, facilitating professional education, and providing programs and services that help people with MS and their families move their lives forward.

The Society's MS Navigators will work with you to help identify solutions and provide access to the resources you seek. To reach an MS Navigator, please call (800) 344-4867 (800-FIGHT-MS) or visit us online at [www.nationalmssociety.org](http://www.nationalmssociety.org). We even have a special Veteran's page on our website at [www.nationalmssociety.org/veterans](http://www.nationalmssociety.org/veterans).

We offer personalized information and answers



to your questions. We can connect you to local resources, programs, and services, including: information for people newly diagnosed, financial assistance and planning programs, employment programs, wellness programs, peer to peer connection opportunities, and an on-line community for Veterans. We offer a wealth of MS educational resources (some in Spanish) including: publications, a newsletter, Momentum magazine, and videos.

The Society has special programs for family members, care partners, and several specifically for children and teens. To learn more, please visit [www.nationalmssociety.org/familymatters](http://www.nationalmssociety.org/familymatters). We offer a scholarship program to help qualified students who have been diagnosed with MS or have a parent with MS achieve their dreams of going to college. Please go to [www.nationalmssociety.org/Scholarship](http://www.nationalmssociety.org/Scholarship) for more information or call (800) 344-4867.

The Society also invites you to contact us if you are seeking volunteer opportunities -- whether it be as a peer support leader, participant, or team captain for Bike MS or Walk MS, or by becoming an MS activist. Tell your story to help raise awareness about MS and the needs of people affected by MS, and help to educate public officials and drive change.

Reach out to us, we want to hear from you and be your partner to help you live your best life!

*Deborah Hertz, MPH - National MS Society*

# STRESS AND MS: CAN MEDITATION HELP?

Having MS can be incredibly stressful. Symptoms are unpredictable and can make it difficult to work, raise a family, or socialize; medications are expensive and come with a host of side effects. Many people report that stress aggravates their MS, and recent research confirms a connection between stress and worsening neurological symptoms. Thus, stress-management is an essential component of a comprehensive MS treatment plan.

Many of the stressful situations we experience cannot be immediately changed (you probably can't tell your in-laws that you're done spending holidays together or your kids to take a hike until they are 25). If you can't remove a specific stressor in your life then the next best thing is to change your relationship to it, and meditation is one way to accomplish this.

## WHAT IS MEDITATION?

Meditation is a mental exercise. It's common for people to think that meditation is about "clearing your mind" or creating a "blank mental slate", but this isn't accurate. Meditation is actually a process of getting to know your mind. There are many different types of meditation. Some forms encourage participants to focus their attention on the breath, other forms suggest participants focus on a word or phrase that is repeated over and over, and still other types of meditation teach that the focus should be on one's internal experience: thoughts, feelings, and sensations.

While specific techniques may vary from one type to another, all meditative practices help cultivate self-observation, awareness, concentration, emotional regulation, and an attitude of acceptance. By practicing meditation, you can learn the patterns and habits of your mind, and then find new ways of approaching stressful life events that can lead to more satisfying and healthy experiences.



## LEARN MORE ABOUT MS!

MSCoE produced free DVD's from our live education programs. They are a great way to learn about MS in the comfort of your home.

- ▶ BOWEL AND BLADDER MANAGEMENT IN MS
- ▶ MS AND EMOTIONAL DISORDERS: APPROACH TO MANAGEMENT
- ▶ MS, COGNITION, AND BRAIN IMAGING: UNDERSTANDING COGNITIVE DYSFUNCTION
- ▶ MS MODIFIABLE RISK FACTORS
- ▶ PAIN AND PALLIATIVE CARE IN MS
- ▶ SEXUAL INTIMACY AND MS
- ▶ STAYING MOBILE WITH MS PART I AND II: MOBILITY FOR PEOPLE WITH MS AND WHEELED MOBILITY AND MS

If you are interested in receiving free DVD's, call (800) 329-8387, ext. 62433 or send an email to [MSCentersofExcellence@va.gov](mailto:MSCentersofExcellence@va.gov).

## WHAT CAN MEDITATION DO FOR ME?

Regardless of the type of meditation, the general practice of focusing attention inward can induce changes in neural, immune, and endocrine function that lead to increased relaxation and improved physical and mental well-being. While research has yet to fully demonstrate how meditation effects change, studies have shown meditation can improve common MS symptoms, including fatigue, pain, sleep disturbance, depression, anxiety, and stress. More than just symptom management, meditation practice can empower participants by enhancing self-esteem, improving coping strategies, imparting a sense of control, and improving overall quality of life.

Meditation is a skill that must be practiced; the more you do it, the better the results. Like a muscle that needs exercise to become stronger, setting aside a few minutes each day to focus your attention will allow you to more readily access the physical and emotional benefits. Regular meditative practice will strengthen the neural connections associated with relaxation and emotional regulation, and with practice you can access these connections in



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your day-to-day encounters with brief “meditative moments.” Just a few focused breaths or a brief mindful reflection can create space between a stressful encounter and a habitual response, allowing your physiology (the way living things or any of their parts function) to shift and providing you more time for thoughtful action in a way that will help manage stress.

### **HOW CAN I GET STARTED?**

The demands of daily life are unlikely to disappear, but your response to these demands can change and that will in turn have a positive effect on your physiology. Commit to caring for yourself by making your stress-management plan as high a priority as taking your medications or nutritional supplements. There are many different ways to get started: The Mindful Awareness Research Center at University of California, Los Angeles (UCLA) has a wonderful website with many resources, including free guided meditations as well as more in-depth online courses

in meditation. Check out [www.headspace.com](http://www.headspace.com). This site provides free, daily, 10 minute guided sessions that you can listen to whenever it’s convenient (they even have a free app for your smart phone!). Consider reading *Full Catastrophe Living* by Jon Kabat-Zinn, PhD, or listen to his audiobook series entitled *Guided Mindfulness Meditation*. Or, find a local Mindfulness-based Stress Reduction class and join others as they learn how to focus attention inward. Interested in learning more about the science behind meditation? The books *Mindsight* and *The Mindful Brain* by Dan Siegel, MD, describe the neurobiological effects of meditative practice and how these effects improve health and wellbeing. There are many, many resources out there, so enjoy the exploratory process of finding a method that works for you and start crafting your own meditative practice today.

*Angela Senders, ND, MCR - Oregon Health  
& Science University*